



CDC's  
National Center on  
Birth Defects and Developmental Disabilities

# Connection

*Birth Defects & Developmental Disabilities  
Hereditary Blood Disorders  
Human Development and Disability*

December 2004

Volume 1, Number 4

## IN THE SPOTLIGHT

### “LEARN THE SIGNS. ACT EARLY”

#### AUTISM AWARENESS CAMPAIGN SOON TO BE UNDERWAY

N CBDDD, with the support of the U.S. Department of Health and Human Services and the Interagency Autism Coordinating Council and the complementary efforts of partner organizations, is launching a national education and action campaign to teach parents how to recognize the early warning signs of developmental disorders, including autism. The purpose of the campaign, as the name implies, is to encourage parents, health professionals, and child care providers to learn the signs and act early. The American Academy of Pediatrics, Autism Coalition, Autism Society of America, Cure Autism Now, First Signs, Organization for Autism Research, and National Alliance for Autism Research are among those we are working with to develop and implement the campaign.

This campaign is targeted at parents with children younger than 4 years of age, as well as child care providers and health care professionals. Its core message is that a child's growth should not be judged by physical measures alone. The developmental milestones that mark a child's social, cognitive, language, and motor skill development should also be taken into account. Early research with target audience groups has revealed that most parents and many health care professionals are not aware of these developmental milestones and of the importance in acting early to detect and deal with developmental delays. The campaign will reach health care providers, parents, and child care providers through various outreach and training opportunities throughout the year.

With this information, four key objectives have been developed for this campaign:

- Educate parents on key developmental milestones.
- Increase health care and child care provider awareness of the importance of early diagnosis and treatment of developmental disabilities such as autism.
- Increase parent-provider dialogue on the topic of child development and developmental disorders.
- Increase early action in dealing with childhood developmental disorders. Specifically, seek to increase screenings and early intervention among children with potential developmental disorders.

(Continued on page 2)

## THIS ISSUE

“Learn the Signs. Act Early”  
Autism Campaign

Director's Corner

Bleeding and Clotting  
Disorders in Women

Update on the Planning of  
the National Children's  
Health Study

CDC's EHDI Works With  
States To Share Information  
On-Line

MMWR RR on Newborn  
Screening for CF

In Memoriam:  
Christopher Reeve

## Quote for the Day

For last year's words belong  
to last year's language  
And next year's words await  
another voice.  
And to make an end is to  
make a beginning.  
T.S. Eliot

(Continued from page 1)

The major components of the campaign include outreach to health care professionals, a targeted educational media campaign for parents, and creation of public-private partnerships to expand dissemination of campaign messages. To achieve these and other campaign goals, NCBDDD has already collected baseline consumer data, developed a resource kit for health care professionals, and distributed press releases and an e-card for health care professionals. In October, a media briefing featuring NCBDDD Director Dr. José Cordero and Dr. Catherine Rice from the Developmental Disabilities Team was held in New York City for the purpose of informing publications representatives of the details of the campaign. Dr. Julie Gerberding, Director, CDC, addressed the agency's position via a taped message. In addition, NCBDDD has conducted partner training sessions in New York; Houston; Los Angeles; Washington, D.C.; and Chicago. Other anticipated activities include collecting baseline health care professional data, launching a direct-to-consumer campaign, and developing child care provider outreach materials and strategies.

For more information on this campaign, visit the website at [www.cdc.gov/actearly](http://www.cdc.gov/actearly)

## Director's Corner

I have chosen not to prepare a formal Director's Corner for this issue. Instead, let me take this opportunity to wish you and yours a Happy Holiday and a Wondrous New Year. Also, please accept my thanks for all of your hard work during 2004. NCBDDD staff and partners have achieved marvelous things through our joint efforts, and I look forward to accomplishing even more in 2005.



A handwritten signature in black ink that reads "José F. Cordero". The signature is fluid and cursive, with the first name "José" being more prominent.

José F. Cordero, MD, MPH  
Assistant Surgeon General  
Director, National Center on Birth Defects  
and Developmental Disabilities

## Bleeding and Clotting Disorders in Women

Bleeding and clotting disorders could affect as many as 2 million women in this country. These disorders, if undiagnosed, can affect women's health because of their relationship to reproductive issues, and possible serious bleeding and complications from childbirth, injury, or surgery. Often presenting initially as heavy menstrual bleeding (termed menorrhagia), the most common bleeding disorder is von Willebrand disease (VWD), which results from a deficiency or defect in the production of a protein that makes blood clot. (VWD occurs in both men and women; however, women are more likely to notice symptoms because of heavy or abnormal menstrual cycles and bleeding after childbirth.) Despite the severity of these conditions, it is only recently that they have received attention in the public health arena.

Even before the Division of Hereditary Blood Disorders (DHBD) became part of NCBDDD, the division (formerly in the National Center for Infectious Diseases) was working to advance current understanding about these medical conditions. In collaboration with the Rollins School of Public

Health at Emory University, DHBD surveyed members of the Georgia Chapter of the American College of Obstetricians and Gynecologists (ACOG) to identify their diagnosis and treatment methods for menorrhagia and their perceptions about and experience with bleeding disorders (especially VWD). The results of that survey, reported by Anne Dilley (a former epidemiologist in DHBD) in her article "Bleeding Disorders in Women: The CDC Program," revealed that approximately 10% of their patients each year reported symptoms of menorrhagia (a percentage equivalent to approximately 3 million women annually). Moreover, in roughly half of these cases, no cause could be found. Nonetheless, only 3% of the physicians said that they would consider VWD as a likely cause when offered that alternative among a group of probable causes. Coupled with this statistic was another that was equally disturbing. When this same group was further queried as to what percentage of a hypothetical group of 1,000 women reporting menorrhagia would be doing so as a result of an inherited bleeding disorder, these physicians answered "less than 1%." What this fig-

ure reveals is the paucity of statistical information and the need for awareness of this condition by the health care community.

As a result of the findings of that study, CDC determined that the underreporting of bleeding disorders among women to be a “problem of public health importance.” Because of that determination, CDC currently is working with the Robert Wood Johnson Medical School to test a questionnaire that will assist physicians to identify patients with menorrhagia who might have a bleeding disorder. Also as a result (in part) of the study and the division's work with others in the bleeding disorders community, in December 2001 ACOG recommended more extensive screening for VWD among likely patients.

This action has precipitated CDC funding of and active participation in a multicenter study to further examine this condition and develop proposals for treatment and management options that are in the best interests of the patients. It has also led to CDC funding of other programs, including “Project Red Flag,” which is a public awareness campaign being conducted by the National Hemophilia Foundation to help women and their health care providers recognize the symptoms of bleeding disorders.

DHBD participated in another public health venue at the National Hemophilia Foundation Annual Meeting, November 4 through 6, 2004, in Dallas, Texas. Several pre-conferences were held on topics of specific interest. One of these, “Toward Consensus on Diagnosis and Management of Women With Bleeding Disorders,” featured speakers and participants from DHBD. Among those cochairing or presenting, or both, at these sessions were

- Sally Crudder, Acting Director of DHBD, who cochaired a session entitled “HTC Network: Health Care Services for Women”;
- Nicole Dowling, Acting Team Leader for Surveillance and Epidemiology, who presented on “Prevalence of VWD and Other Bleeding Disorders” and cochaired the session “State of the Art: Treatment of Menorrhagia”; and
- Connie Miller, Director of the Hemostatic Protein Laboratory, who cochaired the session “State of the Art: Diagnosis”

As DHBD participates in these and other efforts to identify bleeding disorders and to develop treatment and management methods, the contributions of staff and partners to these endeavors continue to hearten all who are affected by these disorders.

## Update on the Planning of the National Children's Health Study

The Children's Health Act of 2000 authorized the National Institute of Child Health and Human Development (NICHD), along with a consortium of federal agencies—including the U.S. Environmental Protection Agency (EPA), the Centers for Disease Control and Prevention (CDC), and the National Institute of Environmental Health Sciences (NIEHS)—to “conduct a national longitudinal study of environmental influences (including physical, chemical, biological, and psychosocial) on children's health and development.” Because children have a special vulnerability to a wide array of exposures in their physical and social environments, this study—the National Children's Study (NCS)—will focus on the interaction of biologic, genetic, social, and environmental factors to better understand their roles in disease etiology and to increase understanding of the origin of health disparities. With a longitudinal design and a life-stage approach, in which children will be studied at several ages as they grow and develop, the NCS will include approximately 100,000 children across the United States identified before birth and followed through birth and childhood, and into adulthood. The size of the study will enable identification of subtle but important effects of low-level environmental exposures that could affect healthy development.

The NCS will be hypothesis-driven to define the sample, design, and measures to be included. The sample proposed will be as generalizable as possible to the U.S. population. The study will enable testing of hypotheses regarding the timing (during pregnancy, infancy, and childhood) of environmental exposures, and will allow their effects to be measured. Most significantly, the study will allow evaluation of the interrelationships between many exposures over time, genetics, and variations in disease severity. For example, genetics, diet, physical activity, cultural attitudes, education, and economics can all act together to influence obesity. Many of these same factors also influence the development of diabetes and asthma, and obesity itself is a risk factor for both diabetes and asthma. These interrelationships will be explored and the life stages of greatest susceptibility identified using the data collected by the NCS. The NCS also is examining the possibility of enrolling at least some women prior to pregnancy to be able to assess fertility and early gestation outcomes. Sample and data storage will be a major component of data collection and, as such, will provide a significant national resource for addressing current and future questions and studies. Multiple pathways of exposure will be evaluated to estimate exposure to compounds or agents of interest. Biological samples that allow measurement of biomarkers of exposures and outcomes will be collected. Known environmental exposures that affect the health and

development of children will be studied. Interactions of these with genetic factors will also be of interest. Exposures will include a number of factors (e.g., pesticides, air pollution, tobacco smoke, and parental alcohol use), inflammation and infections, nutrition of mother and child, and family and societal factors.

Five core themes have been identified for the study that represent some of the most pressing public health concerns in the United States today. These core themes are: (1) pregnancy-related outcomes; (2) asthma; (3) learning, behavior, and mental health; (4) injury; and (5) obesity, diabetes, and physical development.

The lead agencies—NICHD, EPA, CDC, and NIEHS—have been conducting pilot and methods development studies, reviews and white papers, and workshops to explore and examine various measurements and procedures for possible inclusion in the NCS. These include improved

exposure measurement methodologies; innovative technologies for collecting data to reduce participant burden and improve the accuracy of measures; improved methods for obtaining biological samples for genetic analyses; appropriate measures of the physical and social environments; appropriate sampling design for recruiting participants in the study; and community engagement, outreach, and communication.

Current efforts are focused on development of the protocol, defining the sampling design, completing workshops and pilot studies to address a number of measurement issues, securing funding for launching the NCS in 2005, and overseeing the multiple contractual efforts necessary to launch and conduct the study. Efforts are also being made to explore public-private partnerships that will aid in the funding of the NCS. To learn more about the National Children's Study, contact the National Children's Study via e-mail at [NCS@mail.nih.gov](mailto:NCS@mail.nih.gov), or via the Internet at [www.nationalchildrensstudy.gov](http://www.nationalchildrensstudy.gov).

## CDC's EHDI Works With States To Share Information On-Line

Early Hearing Detection and Intervention (EHDI) programs across the country are working to ensure all infants and children with hearing loss are identified and enrolled in appropriate intervention services. While the goals of EHDI programs are similar across the country, programs vary from state to state. Recognizing the need to provide accessible information about these programs to each state and territory, CDC's EHDI Team in the Division of Human Development and Disability at the National Center on Birth Defects and Developmental Disabilities introduced the state profile, which enables programs to learn from each others' successes and challenges.

In summer 2001, the CDC EHDI program began designing the state profile to compile information about state and territorial EHDI programs into one comprehensive resource. At that time, the state profile comprised three modules: the master profile, the travel profile, and the on-line profile. The master profile contained nearly all of the questions that could be asked about a state EHDI program; the travel profile was a subset of the master profile, containing questions that could be asked during site visits; and the on-line profile was a subset of 15 core questions and

answers. During the February 2002 EHDI conference, the CDC EHDI program piloted the on-line profile.

Based on initial feedback, a second version was developed. That on-line version included information that was originally part of both the travel and the master profiles (which were eliminated). Its release in summer 2003 marked a significant improvement in functionality. The new version included support for different surveys, divided into subsets or chapters of related questions. In addition, annual state-reported data from the directors of speech and hearing programs and state health welfare agencies were imported into the state profile. Answers to hundreds of questions were stored in this online and searchable state profile. Designated state EHDI personnel also were able to add data through a secure web-based interface.

Subsequently, the on-line state profile made great progress towards becoming a valuable tool. The web-based interface was visually enhanced to match the identity of the EHDI website. Querying for information was broken down into a simple three-step process with instructions clearly marked. The most notable feature of this revised

### External Partners Group

Interested in working together with other NCBDDD partners on mutual goals? Join the External Partners Group today! For more information, contact Barbara Kilbourne at 404-498-3084, or [BKilbourne@cdc.gov](mailto:BKilbourne@cdc.gov).



third version, which is currently in use, is the approval process for state-level changes. When a state logs into the profile, changes an answer, and saves the update, an email is sent to a CDC EHDI mailbox (ehdiprofile@cdc.gov). Dedicated CDC EHDI staff check the mailbox daily to review and, if appropriate, approve changes made by states. Changes are easily tracked by archived emails. In addition, states can receive reports of questions that they have not answered in order to know what they need to respond to.

In the first month this third version was available, 13 states logged in and updated or added new information to 165 questions. The CDC EHDI group is now sending out promotional emails and tracking the use of the profile after each reminder. This way, the CDC EHDI Team can assess how up-to-date the states' answers are. Rather than researching the answers to these questions themselves, CDC EHDI staff can rely on states, which know their programs best, to take the lead, while still monitoring the information that appears on the website for correctness.

The state profile will have some exciting new developments in the near future. A set of questions related to early intervention and codesigned by the U.S. Department of Education soon will be added to the profile. Also, statistics on the number of births, screenings, and referrals will be available, and will be accessible not only by state but also by geographic region.

Throughout its development, the state profile has included information about all aspects of the EHDI process, such as program structure, screening and referral procedures, tracking and surveillance systems, and educational materials. A key objective of this resource is to assist states in program planning and evaluation, and to inform parents, other government agencies, and providers about EHDI programs across the United States and its territories. With continued refinement and enhancement, the state profile will continue to improve its utility.

## Ch-Ch-Ch Changes at NCBDDD

**Coleen Boyle** formerly Associate Director for Science, has accepted the position of Director, Division of Birth Defects and Developmental Disabilities.

**Carol Strain** has agreed to serve as Acting Team Leader for the Disability and Health Team in the Division of Human Development and Disability.

**Christine Prue** has stepped in to temporarily replace **Katherine Lyon Daniel** as Acting Associate Director of the Behavioral Science and Health Education (BSHE) Team while Katherine is on maternity leave.

## MMWR RR on Newborn Screening for CF

An *MMWR Recommendations and Reports* on newborn screening for cystic fibrosis (CF) was published on October 15, 2004. The report was based on a workshop held in Atlanta in November 2003, and cosponsored by the Centers for Disease Control and Prevention (CDC) and the Cystic Fibrosis Foundation (CFF). The report reviews the evidence of benefits and harms from early detection through screening of newborn infants, focusing on new evidence that has been gathered since a previous workshop in 1997. The report concludes that there is now sufficient evidence of benefit to justify including CF in routine newborn screening panels, although states must weigh the moderate benefit from screening for CF together with state priorities and resources. The report recommends that states, when considering whether to add CF, carefully consider implementation issues to ensure that more good than harm results from screening. The report was prepared by a seven-person writing team led by Scott Grosse and Coleen Boyle of the National Center on Birth Defects and Developmental Disabilities, with members from academic, state, and other federal institutions. The CFF issued a press release to coincide with publication of the report urging all states to include CF in newborn screening panels.

**Martha Alexander** will be Acting Deputy Director of the BSHE Team until a replacement for Katherine Galatas (who left us in August) can be found.

**Sally Brocksen** has joined the Developmental Disabilities (DD) Team as the program manager for the Metropolitan Atlanta Developmental Disabilities Surveillance Program.

**Anita Washington**, an employee of Battelle, is the new Autism and Developmental Disabilities Monitoring Network Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology (ADDM CADDRE) Surveillance Project Coordinator with the DD Team.

## In Memoriam: Christopher Reeve

When Christopher Reeve, stage and screen actor and disability activist, died on Sunday, October 10, the disability community as a whole and we at NCBDDD in particular lost a good friend and great inspiration. NCBDDD's link with Reeve's work to advance the causes important to the disability community, particularly those with spinal cord injuries, was forged early. Dana, Christopher's wife, spoke at our first national conference in Atlanta in 2002. NCBDDD's Disability and Health Team now has a cooperative agreement with the Christopher Reeve Paralysis Foundation to support a national Paralysis Resource Center that serves as a national coordinating facility to provide educational materials, referral services, and self-help guidance to people with paralysis and their families, and to support research that increases our understanding of the impact of paralysis and secondary conditions.

Best known as "Superman" on screen, to many in the disability community, Reeve achieved true superman status for his heroic efforts to bring the problems and concerns of people with disabilities to the attention of the world and for his advocacy with government and private entities to provide more funding for research on spinal cord injury. Reeve, who was 52 at the time of his death, was at the peak of his professional career in 1995 when a fall from horseback injured his spinal column and left him paralyzed below the neck. Reeve rallied from his injury to become a highly visible advocate for more research into treatment, and hopefully a cure, for spinal cord injuries. He appeared on television, in front of live audiences, and before Congress to press for additional funding for such research, including within the controversial area of stem cell research. He founded the Christopher Reeve Foundation in 1996, also with the

purpose of achieving a cure for paralysis.

In 1999, his foundation partnered with the American Paralysis Association under the name of the Christopher

Reeve Paralysis Foundation (CRPF)

to help direct more than \$22 million in strategic grants into proven research channels that included more than 400 investigators worldwide.

Among the CRPF's projects are the Christopher and Dana Reeve Paralysis



Resource Center (PRC). The first of its kind, this resource facility was "created to establish a single, focused national resource on paralysis." In addition to providing timely and quality information, in the next year, the PRC will award \$600,000 in Quality of Life grants. These grants make funds available to community groups whose purpose is to improve the daily lives of people with disabilities, particularly those with spinal cord injuries. The PRC is also fostering a Paralysis Task Force comprising public and private organizations that will develop a national public health action plan on paralysis, including similar mobility limitations. This task force includes several NCBDDD state partners.

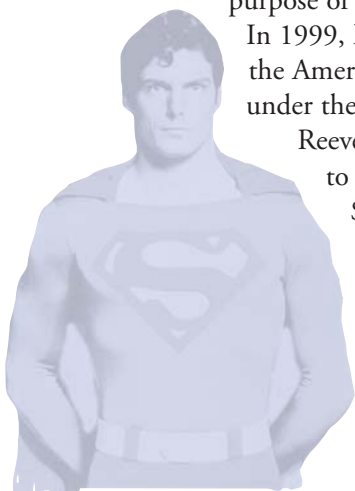
With the wonderful life he lived and the inspiring example he set, Reeve will long be remembered. In life, there are reel heroes and real heroes. Christopher Reeve was both.

---

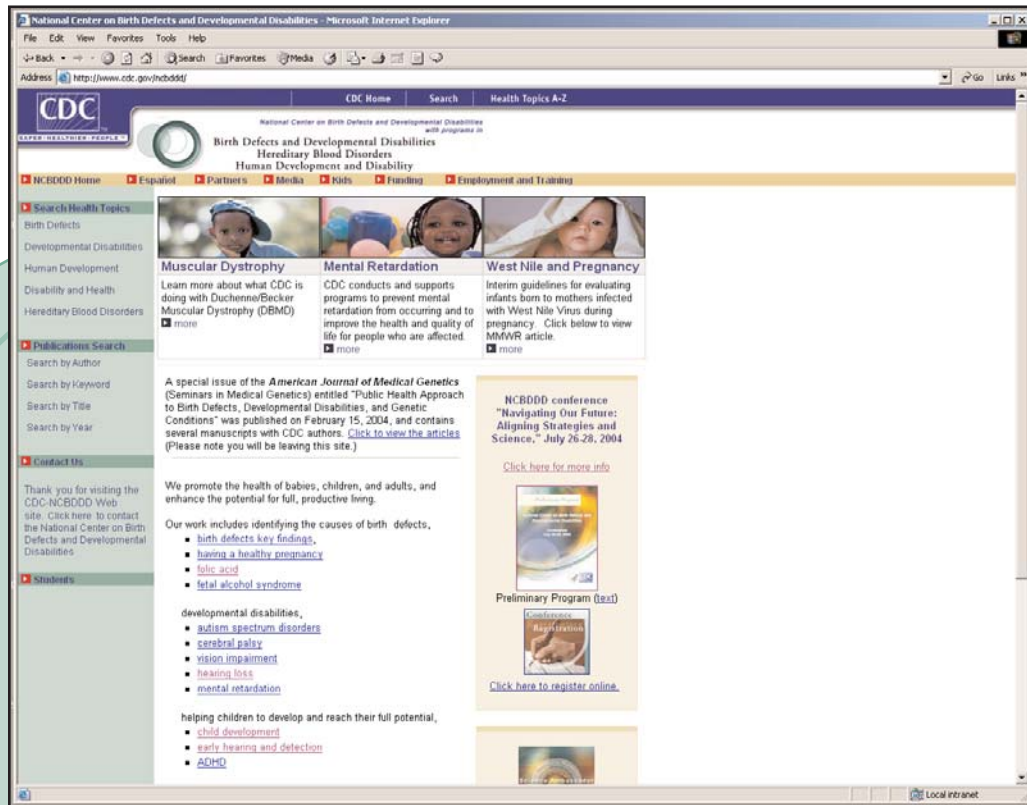
"A hero is  
an ordinary  
individual who  
finds the strength  
to persevere and  
endure in spite of  
overwhelming  
obstacles."

— Christopher Reeve

---



Visit the NCBDDD InTERnet at <http://www.cdc.gov/ncbddd>



and the InTRAnet at <http://inside.ncbddd.cdc.gov> (CDC and HHS employees only)

